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2023

# communication **matters**

**Always assume competence: SLT in a residential rehab setting**

Better Start Literacy Approach • NZ Dementia Mate Wareware Action Plan

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**Cover:** Oystercatcher by Sharat Rao

Please contact the editor with your ideas at any time: [editor@speechtherapy.org.nz](mailto:editor@speechtherapy.org.nz)

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# Artist statement

Sharat Rao



Sharat Rao is based in Whangaparāoa. He has been participating in regular art therapy since January 2023.

## What inspired you to do this painting?

I paint together with my father after we get coffee every Wednesday. I chose the oystercatcher by accident, I liked the photo.

## When did you start painting?

I started painting in January 2023. I paint for two hours every Wednesday.

## What do you enjoy about painting?

I feel more focused when I'm painting. I feel more fantastic when I'm painting! ●

If you have any kiritaki / clients who would like to contribute art to *Communication Matters*, email editor Emma Wollum to arrange an interview! [editor@speechtherapy.org.nz](mailto:editor@speechtherapy.org.nz)



Left:  
Painting  
progress



Left:  
Final  
painting

# Te Reo o Te Kaumatua Nā Rukingi Haupapa

Rukingi Haupapa, Kaumatua



Ngā mihi

**Raumati** (summer) normally is about Christmas holidays and New Year festivities with beautiful weather and sunny days. However, 2022 and into 2023 has been everything else but that.

**He mihi aroha ki a koutou e pēhi nei, e taumaha nei i ngā āhuatanga o te rangi, o te huarere.** (Commiserations to all who have been terribly affected by natural events). **Kia kaha, kia māia.**

**Mā te Wāhi Ngaro tātou e manaaki e arahi kia puta ki Te Whai Ao, ki Te Ao Mārama** (Be strong, be brave. May the gods guide and lead us to dawn and a new, beautiful day).

## 2022 Ngāhuru to 2023 Ngāhuru

The last 12 months have been busy with:

- changes on the NZSTA board from President to portfolio holders
- holding the NZSTA symposium and AGM in Christchurch
- everything else in between, including SLT work and life

Great news! On March 3–5 the second Māori SLT wānanga took place at Te Kuirau marae, Rotorua. There were many

reasons ‘why’, but the main purpose for me was whakawhanaungatanga = meeting, greeting and sharing thoughts about how we can improve SLT work and supports through ‘cultural eyes’. It was a massive job in terms of juggling calendars, study and families, and ensuring that as many people as possible could attend. A big thank you to Hana and the NZSTA board for supporting the wānanga. A big mihi also to the 34 SLTs who sacrificed their precious time to take part and help. Below is a picture of around 60% of the attendees (the others pretended to be paparazzi taking the photo....)

If you want to be with other SLTs on a marae and talk about culture in SLT & NZSTA mahi – do something about it. Contact your cultural advisor, kaumātua, regional SLT committee, and NZSTA board members. Equity and culture is important to all. The SLTs above did just that, which is why it happened.

**Nareira, kia kaha, kia māia, kia tere!!**

(Therefore, be strong, be brave & be quick!!) •

Nākū noa.

**Rukingi**



Above: Te Kuirau marae, Rotorua

Ko Pukeroaoruawhata te maunga

Ko te Utuhina te awa

Ko Te Arawa te waka

Ko Ngāti Whakaue te iwi

Ko Ngāti Te Rorooteangi me  
Ngāti Turipuku ngā hapu

Ko Te Rorooteangi rāua ko  
Kaimatai ngā tūpuna whare

Ko Te Kuirau te marae

# First words

## Kupu tuatahi

Su Hui Lim, Professional Standards, NZSTA



It felt so long ago. After high school, I was originally keen on becoming a doctor, but one day I read a passage in a career magazine about speech therapy.

It triggered interest in me and I wanted to find out more about speech-language therapy as a career. So, I went to the local hospital in my hometown, Melaka General Hospital (Melaka GH) and met with the speech-language therapists. I was fortunate enough to be given an opportunity to observe a bit of their day-to-day work. I realised that this was the career that I was looking for; I applied and got in to study Speech Sciences at the National University of Malaysia. Having completed my studies, I went back to the place I first learnt about speech-language therapy, Melaka GH, a hospital with about 800 beds where I worked for nearly 4 years.

Halfway through, I was left as the sole speech-language therapist in the region due to staff shortages and limited resources. Looking back, it was the most daunting and rewarding time of my career. Often, I was responsible for running the clinic, completing monthly and yearly reports for the service, and providing outreach services at the local special education school and army medical centre despite only a year's experience. During that time I was

constantly learning, questioning, and being open to trying out new things. As a result, I knew I needed more support than just self-learning, so I came to New Zealand and completed an MSc in Speech & Language Sciences at the University of Canterbury.

Today, I work at Taranaki Base Hospital and Hāwera Hospital, alongside seven other supportive colleagues. I enjoy working with both paediatric and adult populations in addressing their feeding and swallowing needs. I am fortunate enough to receive support from many other speech-language therapist colleagues across the country, and now it is time for me to contribute. I feel honoured to be given the opportunity to be a board member of the NZSTA and look forward to what is to come. ●

# First words

## Kupu tuatahi

Amy Scott, Communications, NZSTA



Tēnā koutou katoa. Ko Amy Scott tōku ingoa. I mahi ana au hei Pūkenga Matua ki Te Whare Wānanga o Waitaha. I am delighted by my recent appointment to the NZSTA Board.

I have a long history with the NZSTA, serving as a student representative for two years during my undergraduate degree. I am passionate about the role SLTs play in supporting children's literacy and language success, particularly how they can work alongside teachers to advance this.

After completing my degree at the University of Canterbury, with an Honours project focused on dysphagia, I was certain I was going to work in the medical field. Life had other plans however, and I took a job with the Ministry of Education in Ashburton, which ignited a love of literacy and language. After returning to UC to complete my PhD in education in 2011, I was lucky enough to begin working with Professor Gail Gillon on a research grant focused on early literacy success.

Fast forward seven years, and I am now a senior lecturer and programme coordinator for the Better Start Literacy Approach microcredentials in the Child Well-being Research Institute at the University of Canterbury. This role includes teaching and coordination of over 3500 Year 0-2 teachers and literacy specialists, who are training in and implementing the BSLA in their classrooms across Aotearoa.

I am also a researcher on a number of projects focused on children's early literacy success. My research interests include the development of tools and resources for teachers and whānau, to support the facilitation of early literacy and language success. I have led the advancement of the online assessment tools that form part of the Better Start Literacy Approach, and have particular expertise in the development of multi-purpose assessment tools, which bridge the gap between literacy research and teacher practice.

I am lucky enough to be a māmā to two wonderful small humans, Ivy (7 years old) and Nikau (4 years old), who keep me very busy! I enjoy reading, cooking (and eating), yoga, pilates, and spending time in nature – with or without my children's company!

I am passionate about the revitalisation of te reo Māori and my role as a Pākehā ally in this kaupapa. I have been learning te reo Māori for five years now and am committed to continuing my learning in this space.

I am excited to begin this term and look forward to the challenges and successes that lay ahead. ●

# NZSTA happenings and upcoming events

 2023

**NZSTA Board Meetings**  
**August / September TBC**  
**27 November** – Tāmaki Makaurau / Auckland

 11-12 JULY

**Ako Ararau Māori Expo 2023**  
Kirikiriroa / Hamilton  
More information available at:  
**akoararau.nz**

 20-24 AUG

**32<sup>nd</sup> World Congress of the IALP**  
Theme:  
Together Towards Tomorrow

 26-30 JUN

**Literacy for all intensive course – presented by Dr Sally Clendon and Jane Farrell**  
Tāmaki Makaurau / Auckland – Victory Convention Centre  
More information available at:  
**atanz.org.nz/events/course/literacy-for-all-intensive-course**

 JUL-AUG

**Understanding Dementia Massive Open Online Course (MOOC) – Wicking Dementia Research and Education Centre, University of Tasmania**  
Launches 4 July, new modules released 6 July, 20 July, 3 August, and 24 August  
More information available at:  
**mooc.utas.edu.au**

 23-24 JUN

**Understanding typical movement workshop (TMW) for Paediatric Therapists**  
Independent Living (Royal Oak, Tāmaki Makaurau / Auckland)  
Contact **anne@neurorehabsouth.co.nz** for an application form

 18-24 SEP

**NZSTA Awareness Week**  
Theme: Kotahitanga – Work in partnership with integrity, respect, and humility

 14-16 DEC

**Asia Pacific Society of Speech, Language, and Hearing (APSSLH) Conference 2023**  
Ho Chi Minh City, Vietnam  
More information available at:  
**apsslhconference.net**

Email **editor@speechtherapy.org.nz** to list your event on the NZSTA website in future issues!

# Better Start Literacy Approach workshop for speech-language therapists

Catherine Campbell, SLT, Te Mahau & Claire Winward, Specialist Service Lead, Te Pae Aronui

In February this year a group of enthusiastic – if not slightly apprehensive – SLTs swarmed Christchurch Novotel to be inducted as the first cohort of BSLA trained SLTs.

The BSLA mission is “Systematic and evidence-based teaching approaches to ensure early literacy success for all our tamariki, children”. It has been many years in the making, designed and researched by a team at The University of Canterbury’s Te Whare Wānanga o Waitaha Child Well-being Research Institute, led by Gail Gillion, Amy Scott, Brigid McNeill, Sally Clendon, and Angus McFarlane.

Since 2021, numerous education professionals including teachers, teacher aides, RTLs, and learning support coordinators have been funded by the Ministry of Education to be trained in the BSLA micro-credential course. The February workshop was the first cohort specifically for SLTs.

Thirty-two Ministry of Education SLTs were funded to attend the 2-day

workshop in Christchurch, where the wairua was strong, the coffee flowing, and kōrero continuous.

It was an opportunity to meet the research team, to meet our fellow colleagues from around Aotearoa, to hear first-hand from the evidence base, and to see the mahi in action.

The BSLA website describes the approach as: *“Effective literacy teaching in a child’s first year at school can set them on a pathway to later academic and life success. The Better Start Literacy Approach incorporates the best practices for literacy teaching in phonological awareness, letter sound knowledge and oral language, with small group reading using a systematic reading series”.*

The micro-credential course is an online, self-directed learning programme with weekly Zoom hui, covering all aspects of the approach including modifications for children who may already be known to SLTs. As SLTs we also gained access to the approach’s online assessment and teaching materials, as well as a kete of resources to compliment the mahi. It has been particularly helpful for us to have shared access to the data from the schools already utilising BSLA.

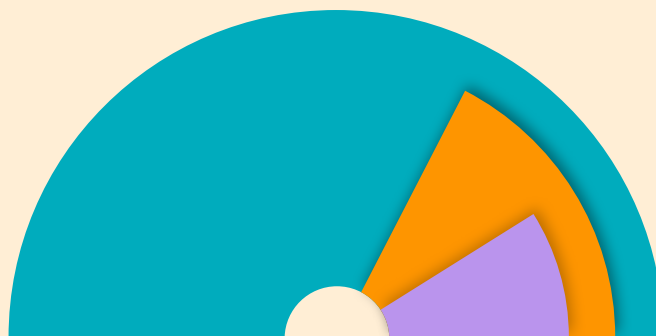
The theoretical underpinnings of BSLA encapsulate Gough and Turner’s The Simple View of Reading, whereby literacy is developed via word recognition and oral language comprehension. Word recognition includes the components of phonological awareness, phonics and fluency, while oral language includes a child’s comprehension plus the breadth and depth of their vocabulary (and background knowledge).



Above:  
Attending the BSLA workshop.



## BSLA: Response to teaching framework aligned to MoE Te Tūāpapa framework



### Te Matua

#### Universal

Strengthens inclusive environments, cultures and practices.

### Te Kāhui

#### Targeted

Offers focused approaches to enhance participation, learning and wellbeing.

### Te Arotahi

#### Tailored

Provides more specific supports for unique needs and contexts.

### Tier 1 Universal/Te Matua

This is a whole-class learning of phoneme awareness, targeted vocabulary through quality children's picture books, oral narrative teaching, and small group reading using the Ready to Read Phonics Plus series. Time frame is 45 minutes, 4 times per week, although this can be split into blocks. For example, the vocabulary and children's book reading can be at a separate time from the phonological awareness activities, depending on the needs of the class.

#### Source

[hepikorua.education.govt.nz/how-we-work/flexible-tailored-model-of-support/](https://hepikorua.education.govt.nz/how-we-work/flexible-tailored-model-of-support/)

### Tier 2 Targeted/Te Kāhui

Small group work which has a more intensive focus on decoding strategies, making and breaking words, and phoneme awareness. The mokopuna in this group may also have support from a literacy specialist. The children in this group will have greater learning needs, and will benefit from the small group and intensive focus of tier 2.

### Tier 3 Tailored/Te Arotahi

This level includes specialist support, such as an SLT, for individuals or for very small group (pairs) work. This involves intensive mahi with making and breaking words, perhaps using the letter blocks, with multiple repetitions, with the aim of building fluency and speed to transfer such skills to reading.

This is Sally Clendon's specialty topic, and she has been a powerhouse of advice for SLTs working in this space. Potential tamariki who may benefit include ākonga known to SLTs who present with childhood apraxia of speech, Down syndrome, learners who use AAC, and others with significant communication challenges.

A unique facet of the BSLA is that it has been purposefully designed to be strength-focused and mana-enhancing, intentionally including whānau as central to their children's success. It was a joy to observe videos of "gold standard" teacher-led sessions during the workshop. Gail Gillion describes it as:

“

A strong international movement towards a strengths-based perspective to supporting children in their learning. Within the Better Start Literacy Approach we focus on what children are achieving, the learning conditions, teaching practices, family, and community supports that will lead to success. We recognise children's emerging capabilities and work hard to increase or strengthen those areas that will facilitate success.”

Other highlights and delights from the workshop were the use of so many culturally appropriate resources with te reo Māori kupu (words) and pictures, the strength of sharing the same understanding and terminology as teachers, connecting with our MoE colleagues, and the fact that this approach has been designed for and based on research involving tamariki in Aotearoa NZ. ●

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#### Further resources

**[betterstartapproach.com](http://betterstartapproach.com) or [hepikorua.education.govt.nz/how-we-work/flexible-tailored-model-of-support](http://hepikorua.education.govt.nz/how-we-work/flexible-tailored-model-of-support)**

Contact the authors for additional references.

## Featured event: 32<sup>nd</sup> World Congress of the IALP

**Dr Karen Brewer (Whakatōhea, Ngaiterangi)**, SLT and kaupapa Māori researcher, Waipapa Taumata Rau University of Auckland

As we prepare to host the 32<sup>nd</sup> World Congress of the IALP in Auckland in August, now is a good time to learn about the IALP (**[ialpasoc.info](http://ialpasoc.info)**). You might even consider becoming a member.

IALP originally stood for "International Association of Logopedics and Phoniatics". It's now known as the "International Association of Communication Sciences and Disorders" (because who knows what logopedics and phoniatics are?) but has kept the acronym IALP. IALP is about to turn 100, with the centenary opening celebrations happening in NZ at the upcoming Congress. Pam Enderby is the past president and will be overseeing the Congress in NZ.

IALP has a global vision to facilitate better understanding, knowledge, and care of all those with communication and swallowing disorders.



The mission of IALP is to improve the quality of life of individuals with disorders of communication, speech, language, voice, hearing, and swallowing. IALP will:

- ✓ facilitate science, education, and clinical practice through international cooperation and collaboration;
- ✓ create and share knowledge, skills and information;
- ✓ provide a platform for international networking and advocacy

IALP is well-connected internationally, with representatives sitting on committees within the WHO and the UN. The NZSTA is an “affiliate society” of the IALP, along with 56 others including SPA, ASHA, and every national SLT-related

association you can possibly imagine (Malta, Japan, Iceland, and many more).

IALP has a number of committees, which address professional issues from a global perspective. Philippa Friary is on the Education Committee. Annette Rotherham and I are on the Aphasia Committee, along with aphasia specialists from Australia, Brazil, USA, Ghana, UK, Germany, and India. It’s difficult to arrange a meeting time across all those time zones, but interesting to discuss aphasia in such an international context. The committee has an emphasis on equity in access to speech-language therapy, and has been running a mentoring programme for clinicians in countries where there are few SLTs and few opportunities for professional development. •

## IALP list the benefits of being an individual member as:

1

Contribute to the infrastructure of IALP’s committees and support its activities.

2

Collaborate with colleagues across the globe on matters of interest to the professions.

3

Attend webinars and composita at reduced rates on specialized topics offered on the IALP website.

4

Benefit from special reduced member rates for registration at the triennial Congress and other scientific meetings sponsored by IALP.

5

Contribute to the global voice to impact the lives of individuals with communication and swallowing disorders.

6

Electronic access to our in-house scientific journal, *Folia Phoniatica et Logopaedica* (6 issues per year, special issues and back issues) and other curated collections.

7

Engage with our vision and mission.



Visit [ialpauckland2023.org](http://ialpauckland2023.org) for more information – the regular registration fee is available until August 18, and registrations can also be purchased onsite.

# “Always assume competence”

## Establishing an SLT service in a residential rehabilitation setting

Saoirse O’Connor, SLT, ABI Rehabilitation

Kia ora! My name is Saoirse (pronounced “seer-sha”) and I am a speech-language therapist from the Emerald Isle of Ireland.



I graduated from University College Cork in 2016 and made the massive leap across the globe to the beautiful Aotearoa in October 2019. I’ve been living and working in Auckland since and every day has been an adventure, to say the very least!

I decided to take on an exciting new challenge at the end of 2021. I took up a post at ABI Rehabilitation in the residential setting. This involves working with clients who are anywhere from a few months up to several years post-acquired brain injury, many of whom have engaged in intensive rehabilitation in the sub-acute setting but are not yet at a place where they are ready to return home. Their client-centred goals may look different, but they are very real and for many, just as important as they were directly post-injury.

Before taking on this role, speech-language therapy input had been very limited in this setting – only requested as required for consultation, specifically in relation to dysphagia management. I was presented with the opportunity to create an SLT service that could provide a more holistic service to our clients

in supporting them to achieve their rehabilitation goals. It was a daunting, but incredibly rewarding challenge.

### Dysphagia management

The amount of dysphagia management that can be done in the residential setting is monumental. Following cough reflex testing, cranial nerve examinations, and videofluoroscopy and FEES assessments (thanks to the support of the incredibly knowledgeable SLTs at North Shore Hospital), we have been able to introduce free water protocols, take clients off of thickened fluids, commence oral trials, and progress to more regular diets. If there is one thing I’ve learnt, it is never too late when it comes to improving swallowing function. A high intensity of SLT input is required for our clients who wish to return to eating and drinking, and to support those able to engage in swallowing manoeuvres, compensatory strategies, and skills-based training. I’ve been blown away by client motivation, even several years down the line. Is there anything more fascinating than the literature on neuroplasticity and swallowing?

“ Ni neart go cur le cheile.”

An Irish proverb meaning there is no strength without unity.

### Augmentative and Alternative Communication

This certainly is a special interest of mine, and it has been a real blessing to see the impact it can make on someone's life, no matter what age they may be. Talklink input has been absolutely invaluable. We started off with some low-tech aids (such as yes/no lanyards, communication passports, communication books and pain boards) to demonstrate how we can provide our kiritaki with more choices throughout their daily routine. Educating staff on a total communication approach has been a huge aspect of the role. We are always striving for autonomous communication for our clients, and we have been successful with introducing some high-tech aids such as dedicated communication devices and eye-gaze technology. “Always assume competence” is my motto, and this has been solidified through this mahi. The responsibility is on us to create opportunities for these people to share their stories and to have their voices heard. Sharing stories and making meaningful connections is what makes us who we are. It forms our identity

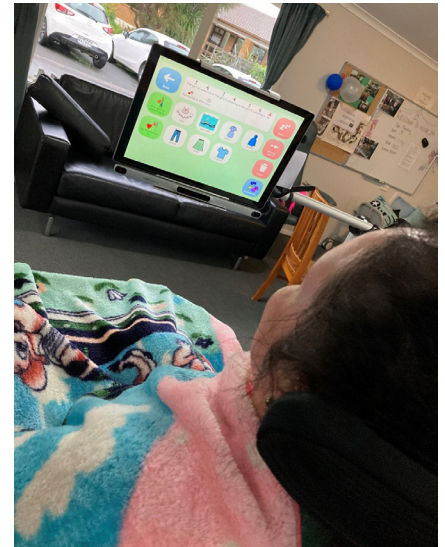
and enables us to make and maintain relationships. I believe it is the greatest gift to be able to support someone else in achieving this.

### Cognitive Communication

To date, our focus has been on carrying out assessments and education sessions with clients, staff, and whānau. Our priority has been to create a more supportive communication environment for clients who present with memory, attention, and executive functioning skill difficulties. Implementing compensatory strategies, and utilising simple tools such as calendars, reminders, and diaries, have achieved great positive differences. My goal for this year is to establish more group intervention to generalise these skills in a more functional setting. I hope to take our mahi out into the community – to shops, restaurants and cafes. Watch this space!

### Long Road Ahead

To summarise, this really is only the tip of the iceberg. Our clients present with complex needs and significant impairments, from aphasia



Above:  
Using AAC in a residential setting.

to motor speech disorders to social communication difficulties. I have been working hard to lay foundations, source resources & assessments, utilise outcome measures, and establish clear clinical care pathways. I am very fortunate to have the support of an incredible team of talented SLTs at the ABI Rehabilitation Intensive service, as none of this work could be carried out without them. I hope to advocate for our kiritaki and the powerful role the SLT has at this point in their rehab journey. ●

I am always open to ideas, suggestions and questions, so please feel free to reach out at  
[Saoirse.oconnor@abi-rehab.co.nz](mailto:Saoirse.oconnor@abi-rehab.co.nz)

# Grief and loss after brain injury

Carole Starr, Author, *To Root & To Rise: Accepting Brain Injury*

Carole Starr is a brain injury survivor, keynote speaker and the author of *To Root & To Rise: Accepting Brain Injury*. These quotes from her book highlight the magnitude of grief and loss experienced by brain injury survivors, and offer hope that it's possible to move forward.



## Grief and loss after brain injury – what it's like

Brain injury launches us into a swirling, dark world. We may be angry about what's happened to us; grieving what we've lost; worrying about what will become of us; frustrated as we try to navigate the complexity of everyday life with a brain that doesn't work the same anymore. Sometimes it feels like our past, present and future have been sacrificed to this horrible injury.

Brain injury changes who you are and what you know about yourself. Many of us feel like different people, with new and unfamiliar limitations, reactions, thoughts, feelings, fears, likes and dislikes. We're strangers to ourselves.

There's so much loss to process; it may seem impossible to face a future with a brain that doesn't work the same anymore.

“Where you are now is not where you'll be one year, two years, five years or ten years from now. Today's challenges can turn into tomorrow's successes.”

Nothing seems easy anymore. Everything is a struggle, a challenge.

The grief over all I'd lost was overwhelming. It was the most intense grief that I'd ever experienced, worse than grief from the loss of loved ones. This time it was me who had died.

So many people didn't seem to understand the life-shaking magnitude of what I was going through. Their words often minimized my symptoms or seemed to express doubt that they were even real. Every comment, even the well-meaning ones, felt like an attack on my sense of self, and on who I was as a person.

I felt so alone, like a stranger among the people who knew me best. I felt that I was a burden to everyone and a failure as an adult.

Brain injury damaged those qualities I'd defined myself by, leaving me feeling lost and worthless. I hated all the ways I'd changed and deeply mourned my loss of self. I doubted whether I was strong enough to cope with all of it.

Coping with brain injury takes every ounce of determination, courage and patience we possess.

### Importance of accepting brain injury

When we've accepted brain injury, we're able to acknowledge the past without getting overwhelmed by emotion. At the same time, we're able to face the future and live within a new normal.

It seems unlikely, but coming to acceptance can be a key that opens the door to happiness and purpose after brain injury. Even though acceptance doesn't change the reality or the challenge of brain injury symptoms, it can change how you experience those symptoms. Acceptance is like looking at the world through a different lens. Coming to terms with brain injury can mean the difference between a mournful life spent looking backward at what was and a meaningful life spent moving forward with what is.

### Beyond grief and loss – creating a new life

Nothing about brain injury is quick and easy. Getting to know and even like your new self is a process, one that takes time. It means focusing on the present, on what is. That's how you begin to find your new life.

Rebuilding one's sense of self is a necessary step in the journey after brain injury.

Actions you can succeed at will propel you forward. When you find something you can do successfully, no matter how small it is, that's where you build from.

Living with brain injury can be a delicate balance between knowing when to try harder and when to just let go and accept what is.

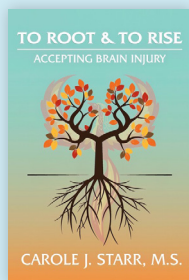
For years, I spiralled between time spent grieving the losses and time spent getting to know the new me. Ever so slowly, my primary focus turned to the present and what I could do.

Paying attention to what I'm proud of now keeps me centred in the present moment, not lost in the past. Instead of focusing on the way life used to be, I put my energies into continuing to create this new life.

Moving on doesn't mean the sadness and loss completely go away. They just become a smaller segment of my daily existence. I'm learning that victory doesn't come from not having those feelings, but rather from knowing how to deal with them.

Brain injury takes so much from us. Find the glimmer of good in it, no matter how small or insignificant it may seem. That can change your focus from looking backward to looking forward.

Where you are now is not where you'll be one year, two years, five years or ten years from now. Today's challenges can turn into tomorrow's successes. Believe that you will continue to grow, change and move forward. ●



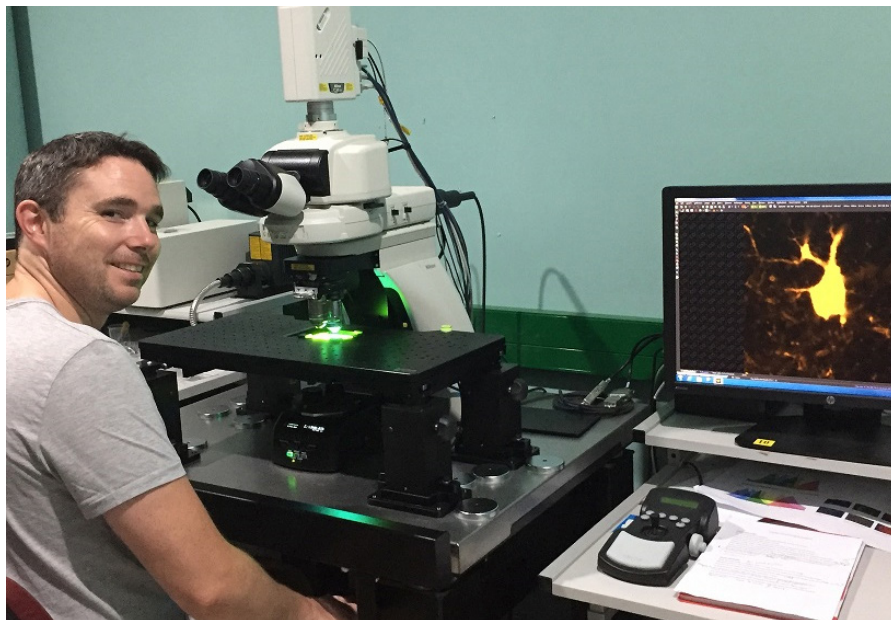
#### **To Root & To Rise: Accepting Brain Injury**

Published May 2017

RRP \$17

# Speech, language, and frontotemporal dementia

Dr Owen Jones, PhD, Research Fellow and Teaching Fellow, University of Otago



Above:  
Dr Owen Jones at work.

When we think of dementia, most of us would picture a condition of advanced age, characterised by confusion and memory loss.

In all likelihood, we would not imagine a disease that primarily affects speech production or comprehension. Yet, such conditions have been known to us since the late 19th century (Pick, 1892; Serieux, 1893). Nowadays we use the term primary progressive aphasia to describe them. Language difficulties are the primary clinical feature, with corresponding atrophy of the left temporal lobe (the location of much of the brain's 'language network') (Gorno-Tempini et al., 2011).

Primary progressive aphasia is usually the result of frontotemporal dementia. This condition is rarer than Alzheimer's disease, and so does not get the same level of coverage. Yet, frontotemporal dementia is actually the most common dementia seen in people under 65. Broadly speaking, the disease manifests in two ways: if the frontal lobes are the main site of damage, patients undergo significant personality changes, poor judgement and inappropriate behaviour; if the temporal lobes are most affected, patients exhibit primary progressive aphasia, either characterised by agrammatic, laboured speech (the nonfluent variant) or deficits in word comprehension and naming (the semantic variant). These variants typically appear before the age of 65 and become



progressively worse. Atrophy will continue to spread throughout the brain, and will eventually lead to widespread loss of function. Typical life expectancy is around 7–8 years from after symptom onset, although this can vary significantly.

As with Alzheimer's, there is no cure for frontotemporal dementia. A number of pharmacological interventions have been trialled (Kaye et al., 2010), but these have largely been aimed at treating the behaviours associated with frontal lobe damage, rather than the speech and language deficits that follow temporal lobe atrophy. They have, in any case, proved to be of limited use, and none have been able to halt the progress of the disease.

Given the lack of pharmaceutical aid, it seems that health professionals with expertise in behavioural interventions might be best placed to address the impact of frontotemporal dementia on daily life. Of note, a growing body of evidence suggests that speech therapy can be beneficial in preserving speech production and naming in primary progressive aphasia, both in the short-term and long-term (as long as a year post-intervention) (Jokel et al., 2014; Tippett et al., 2015; Henry et al., 2019; Kortte & Rogalski, 2013).

Speech-language therapy will not be a cure, but it may be one tool that aids in maintaining function for as long as possible. Accordingly, referral of patients to SLTs has been highlighted as an important step in improving treatment of primary progressive aphasia (Volkmer et al., 2020).

But what about preventing dementia in the first place? We often hear that “prevention is better than a cure”, and this is surely all the more important when no cure exists. So, can we prevent frontotemporal dementia or Alzheimer's? The answer may surprise you. In 2020 the Lancet Commission on Dementia suggested that up to 40% of dementia cases could be attributed to modifiable risk factors that could in theory be negated (Livingston et al., 2020). The biggest factors by far are exercise, diet, and social connectivity. Staying active, eating well, and socialising regularly are all key to successful ageing, it would seem. SLTs certainly have something to offer when it comes to those three factors.

Other things to consider would be to stop smoking and to not drink alcohol, and perhaps one more language-related factor: become bilingual. Bilingualism is associated with a delay of dementia

onset of 4–5 years (Kim et al., 2019). Early bilingualism appears to be best, as this is one way of building up a strong “cognitive reserve” that will offset any loss of function in later life. However, while sooner is better, it's also true that adult language learners can see positive benefits. Adult learners show improved brain connectivity and cognitive performance, even when learning later in life (Bubbico et al., 2019). It's possible that this effect comes from the social aspect of attending a regular class and talking with friends, but either way it's a positive outcome.

In short, speech and language are at the heart of frontotemporal dementia. They are the first abilities that many will lose, and perhaps the most relevant target for any therapeutic intervention. And if you can harness your potential for learning new languages, your brain may just thank you for it later on. Time to sign up for a class? ●

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**Contact the author for additional references.**

# The NZ Dementia Mate Wareware Action Plan: A local response to a global call to action

Annabel Grant, Senior Professional Clinician, Massey University

At the NZSTA symposium in Christchurch last September, we encouraged attendees to think about how the principles of the New Zealand Dementia Action Plan can apply to their practice.

We were fortunate to have had the support of a keyworker from Dementia Canterbury, Erica Collingwood, (also a trained SLT) to share her insights. To set the scene, we highlighted the WHO Global Action Plan on the Public Health Response to Dementia 2017–2025, and the United Nations Convention for the Rights of Persons with a Disability (CRPD). These core documents have clear implications for the work of speech-language therapists, who can provide evidence-based rehabilitation. The recent framing of dementia as a disability inspired us to consider how accessible communication principles and issues of equity and human rights are becoming more salient for this population. A growing body of evidence from international and NZ sources

highlights the integral role of speech-language therapy throughout the journey of a person with dementia, rather than SLT involvement only in assessment, diagnosis, and palliative care. However, the current situation in Aotearoa is described best by Kate Swaffer (a person living with dementia), who has said “we do not receive post-diagnosis rehabilitation or most other allied health services to support our independence or social inclusion”.

In Aotearoa NZ we now have the Mate Wareware Dementia Action Plan 2020–2025, to guide improvements in the quality of life of people living with dementia (mate wareware). The four objectives of the plan were discussed in terms of our SLT role, as summarised:

1

## Reducing the incidence of dementia

SLTs have opportunities to optimise brain health across the lifespan. As social isolation is a modifiable risk factor for dementia, how can we support people to engage socially when communication is difficult?

2

## Supporting people living with dementia (and their whānau) to live their best possible lives

Consider how we can meet the communication support needs of our clients and their communication partners. With dementia recognized as a disability, we should aspire to offer rehabilitation for cognitive impairments affecting communication. Cognitive stimulation therapy manuals are now available in Aotearoa in both English and in te reo Māori.

3

## Building accepting and understanding communities

Stigma and a lack of awareness and understanding can both cause barriers to inclusion. These barriers make it harder for people living with dementia mate wareware, and their support people, to get the help they need. Connect whānau to the Mate Wareware App, and do some awareness-raising in your area.

## Strengthening leadership and capability across the sector

We can prepare our students to deliver quality services which uphold the human rights of people with dementia mate wareware. Significant equity issues exist for kuia and kaumātua living with mate wareware (risk factors and poor access to culturally appropriate health services). SLTs can continue to learn about holistic frameworks which are culturally safe for Māori whānau and other cultures represented in Aotearoa.

## Discussion from the Workshop

Attendees at our workshop identified the need for dedicated FTE for SLT in aged care services, a clear assessment process for dementia and cognitive communication changes, and pathways for referral to SLTs. Workshop participants also acknowledged the need for a streamlined referral process without significant wait times due to the progressive nature of dementia, and access to cognitive stimulation groups. Participants also discussed improving

access to resourcing to provide education to people with dementia and their whānau, and increasing advocacy for the role of speech-language therapy in a person's journey through dementia. The SLTs at the workshop also identified a need for understanding whānau and client perspectives of dementia and cognitive changes.

## What has happened recently?

In the 2022 Budget, \$12 million was allocated for a four year initiative to deliver post-diagnostic support trials, dementia navigators, and innovative respite care, in support of the Action Plan. Despite this progress, Alzheimers NZ Chief Executive Catherine Hall recently restated that support services have reached a tipping point, and nearly 30,000 Kiwis are missing out on support due to the current underfunding.

2023 is an election year. Given the current situation, a way to push for the improvements we discussed in our workshop may be to campaign, by writing to or meeting with your MP. Let them know urgent action is required, as a rapidly growing number of New Zealanders are being diagnosed

## Further resources



Mate Wareware app  
[matewareware.co.nz](https://matewareware.co.nz)



Mate Wareware Dementia Action Plan 2020-2025  
[cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Mateware-Action-Plan.pdf](https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Mateware-Action-Plan.pdf)

with dementia mate wareware, and current funding for services is woefully inadequate. The Alzheimers NZ website has some excellent campaigning information. You can also join the dementia mate wareware network (part of the Governance Ecosystem) and get involved in representing our SLT mahi. ●

[www.nzdementia.org/](https://www.nzdementia.org/)  
**Dementia-Ecosystem**

# The ageing swallow

**Kendrea L. (Focht) Garand, PhD, CScD, CCC-SLP, BCS-S, CBIS, CCRE, Associate Professor,**  
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For decades, we have studied how healthy ageing impacts the swallowing mechanism. Similar to the trunk and limbs, the skeletal musculature comprising the head and neck is not excused from age-related changes impacting its function.

These changes occur in healthy individuals, but can place the system in a state where if disease or injury occurs, the individual has to work at increased capacity, which further depletes their “reserve” (known as homeostasis). This makes it more difficult to recover and can increase the risk of further

impairment. Yet, while an individual can easily compensate for these changes (e.g., chew longer if dentition is affected) without health complications, it remains critical that clinicians be aware of these naturally-occurring changes when considering how their patient is functioning.

## Our project

For our cross-sectional study, we wanted to create a large normative videofluoroscopic swallow study (VFSS) database of healthy, non-dysphagic, community-dwelling adult individuals. This would allow us to contribute to normative reference values that clinicians could then compare their patient data to.

## What we did

We successfully completed 195 VFSSs in individuals ranging from 21 years to 89 years. These individuals did not have a current or previous history of any injury or disease where dysphagia is a recognized symptom. Each VFSS was performed using the Modified Barium Swallow Impairment Profile (MBSImP)<sup>TM</sup> and scoring system developed by Dr. Martin-Harris’ colleagues – a tool used by 8,000 clinicians worldwide in approximately 50 countries. Ten

swallows are performed in the lateral viewing plane, and two swallows are performed in the anterior-posterior viewing plane. The MBSImP assesses 15 different physiologic components across the entire swallow continuum (oral, pharyngeal, esophageal), and includes two efficiency measures (oral and pharyngeal residues). Each component involves giving a score based on the observation by the clinician, ranging from 0–2 or 0–4 depending upon the component. Higher scores indicate worsening function (impairment). We also applied a validated and standardized swallow safety measure – the Penetration-Aspiration Scale. Validated and standardized biomechanical measures (e.g., timing [temporal] and displacement [kinematic] measures) are also beginning to be applied – Analysis of Swallowing Physiology: Events, Kinematics & Timing (ASPEKT) developed by Dr. Steele and colleagues and the Dynamic Swallow Study (DSS) interpretation method developed by Drs. Leonard and Kendall. Reliability within and between raters was established prior to measures being completed. Advanced statistical modelling allowed us to explore how various factors can influence swallowing performance.

## What we found (so far!)



Airway invasion is rare in healthy adults and does not appear to be impacted by age. Specifically, less than 6% of swallows had penetration and less than 1% had aspiration.



Although pharyngeal residue has low amounts when present, older adults are more likely to have it present.



Swallowing behaviours are variable! It can be influenced by both personal factors (age, gender) and bolus factors (volume, viscosity). For example, there is variability in where the bolus is in the pharynx when the pharyngeal swallow onset occurs, particularly for liquids.



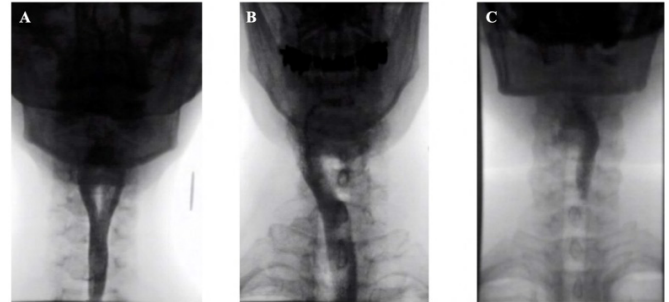
Swallow event durations (e.g., upper esophageal segment opening duration) are typically longer in older adults.



Ageing appears to impact pharyngeal swallowing components more so than oral components.

## Clinical implications

- Presbyphagia refers to age-related alterations in swallowing performance. This can result from tooth loss, altered oropharyngeal sensitivity, and even changes in the cervical spine. Sarcopenia can also contribute to these alterations,



A) No laterality

B) Right-sided laterality

C) Left-sided laterality

### Above:

Examples of pharyngeal laterality in swallowing. Source: Kendrea Garand.

which is described as progressive and generalized loss of skeletal muscle mass and declines in strength.

- Clinicians must be aware of how healthy ageing can impact swallowing. Such changes are not considered pathological.
- Clinicians need to educate the community and other healthcare professionals about an ageing swallow in order to improve identification for when a comprehensive assessment is warranted.
- Comparison of patient data to normative reference values when available are critical within patient documentation.

We are continuing to perform additional analysis, including biomechanical measures. We hope our work helps contribute to clinicians making informed decisions about when and what impairment(s) are present (if present!), severity of these impairments, and what impairments need to be targeted in treatment, in order to inform the care plan. Future work should investigate if we can slow down (or reverse!) progression of these age-related changes. We are encouraged to exercise our trunk and limbs, but should we also be encouraging adults to exercise their swallow muscles? There are investigations underway which are looking to help answer this question. •

References available upon request, contact [kgrand@pitt.edu](mailto:kgrand@pitt.edu) for more information.

# Way To Play, and the Framework for Autism in New Zealand (FANZ) Initiatives from Autism NZ

Tanya Blakey, National Educator, Autism NZ & Jo Charman, National Educator, Autism NZ



## Whaowhia te kete mātauranga Fill the basket of Knowledge

Tanya Blakey and Jo Charman are both national educators for Autism NZ, and are also the respective parents to two young autistic adults. Alongside their colleagues, they have been running Education programmes with Autism NZ since 2010.



### Way To Play

In our capacity as parents to autistic children, we were made aware in the early years that empowering ourselves as the enduring educators was going to be key. Surprisingly, we discovered that there was very little autism education available in New Zealand, not even for professionals working with our children! We wanted to be able to connect in a meaningful way with our kids and have the professionals working with them see them for who they are, working in a joyous and strength-based approach.

As a result of many years' work with several dedicated professionals, whānau, and Oaklynn Special School – Way to Play was created!

The purpose was to simply create a fun programme with a New Zealand flavour,

which is accessible to whānau and early educators, to provide guidance and teaching in how to play joyously with autistic tamariki.

It is essential that we offer several opportunities for playfulness and quality engagement throughout a child's day – this can begin with trusted adults, and continue later with peers as the child grows in confidence. Being present is not enough, shadowing is not enough. If we are shadowing – we may as well be playing and having fun. If it is not fun, there is no learning happening. Relationships work. The first chapter on any resource on Autism should always be 'Build a trusting relationship with that person'. The strategies in Way to Play allow us to do that easily and quickly. We do not need to observe a child for hours- we can simply create a predictable game using a pattern, add a song/jingle to that game, and start varying up the pattern when the child is aware of their role. Now you have a connection, we are communicating, we are together. Bring back the silly, and see what wonderful

“ I found this fun workshop extremely helpful in my role as SLT. How I can use play in early communication skills to feed into later goals in social communication. The mixture of reading material, interactive joyous facilitators and video examples were excellent to solidify the strategies.”

SLT Way to Play participant

things can happen! These interactions may be fleeting, but they are so vital in the child's development.

Play develops the fundamental capacities that are essential for lifelong learning. These capacities include social motivation, imitation, shared and joint attention, serve and return interactions, communicating socially, and playing with peers. This is where the child needs practice. If these capacities are not in place, all other learning becomes challenging, if not impossible.

Through Way To Play, we aim to help participants understand why young autistic children find social interaction stressful, how to overcome that stress and show the simple steps to joyful, and how to purposefully play with tamariki.

Autism NZ has worked alongside countless SLTs demonstrating the Way to Play strategies, which has proved to be invaluable for their mahi with the autistic tamariki on their caseloads.



### FANZ (Framework for Autism in New Zealand)

FANZ is an engaging two-day introductory programme that enables participants to create a framework for understanding and supporting an autistic child or adult. It is a collection of evidence-based strategies and recommendations, delivered in a fun interactive style through video examples. FANZ aims to provide a deeper strengths-based understanding of autism. Analogies are used to create relatable experiences of what it may be like to experience autism, putting the autistic voice at the centre of everything.

Many professionals attending FANZ have commented that it has given them an insight into many of the tangata they support. Whether it be Way to Play, FANZ, or any of the Autism New Zealand programmes offered, our participants

overwhelmingly comment that these programmes have provided 'lightbulb' moments for both whānau and professionals, and that they have gained a deeper understanding from both perspectives.

One SLT commented that she had never been so engaged over a two-day programme. She stated that the interactive, positive nature of the information provided her with invaluable resources and information that she has been able to share with colleagues and with families and whānau of autistic children receiving SLT services.

Both Charman and Blakey have thoroughly enjoyed working alongside the dedicated SLTs they have met through the many programmes offered by Autism NZ. Based on the encouraging feedback from previous participants, they would welcome anyone working in this sector to come along and see what is on offer and have some fun! ●

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Register for programmes at [autismnz.org.nz/programmes/?\\_programmes\\_category=professionals](https://autismnz.org.nz/programmes/?_programmes_category=professionals)

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